NAMI VIRGINIA
Formerly the Virginia Alliance for the Mentally Ill

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Commissioner of Social Security
P.O. Box 17703
Baltimore, MD 21235-7703

RE: Revised Medical Criteria for Evaluating Mental Disorders,
68 Fed. Reg. 12639, Mar. 17, 2003

Dear Commissioner:

People disabled with serious brain disorders often have no alternative but to rely on disability benefits. Thus, the Mental Impairment Listings are vitally important. I am writing in support of the comments submitted by the Consortium for Citizens with Disabilities, and the National Alliance for the Mentally Ill (our national office). These comments are attached.

Thank you for your consideration.

Yours truly,

John J. Baumann
Deputy Director

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Summary of Recommendations Responding to:
Revised Medical Criteria for Evaluating Mental Disorders
Advance Notice of Proposed Rulemaking
68 *Federal Register* 12639, March 17, 2003

In general, the current structure and design of the mental impairment listing works for the purpose of assessing children and adults with mental disorders. The basic structure and approach to the listings were developed by an expert panel appointed by the Social Security Administration prior to the publication of the adult listing in 1985. Based on the adult listing and with significant input from childhood disability experts, SSA published the children's listing in 1990. The structure and approach have stood the test of time and still prove to be practical and workable for the evaluation of adults and children.

There are important updates and refinements that should be included in the listings for adults and children. Specific recommendations are set forth below. These recommendations are for refinements within the current structure of the listing. A major overhaul of the mental disorder listing is not necessary or appropriate. However, if SSA contemplates major overhaul of the listing, then SSA should formally adopt an expert panel process similar to that used prior to the publication of the adult listing in 1985, to ensure careful consideration of all recommendations for and ramifications of change.

Introduction to Mental Disorder Listings: Section 12.00

Assessment of Severity

1. The Introduction (Section 12.00) should be expanded to include Social Security Administration (SSA) policy pronouncements that exist in other sources.

2. SSA should add language to the Introduction and to the "B" criteria making it clear that an "extreme" limitation in one area of functioning satisfies the "B" criteria.

3. SSA should use language from the childhood disability regulations that better defines "marked" and "extreme".

Evidence Issues

1. SSA should provide clear guidance to adjudicators regarding the importance of evidence from all treating non-physician professionals in assessing an individual's limitations.

2. Information from non-physicians who work in licensed clinics or as part of physician-supervised treatment teams should be treated as "medical evidence of record".

3. Where a claimant is unable to describe functional limitations or when self-reported functioning surpasses what would be expected from the medical evidence of record, SSA should encourage the use of a third-party assessment of an adult claimant's functioning.

4. SSA should clarify the Introduction to include information on how to treat work in supported work settings.

Clarification of Drug Use

SSA should provide guidance to adjudicators that the mere fact of drug use is not grounds for denying a claim and that adjudicators must distinguish between cause and effect.

Treatment Affecting Signs and Symptoms

The Introduction should clearly establish that an individual who meets the "B" functional criteria and who has the diagnosis in the "A" criteria (even though signs and symptoms may be controlled by medication) will qualify.

Documentation

SSA should provide guidance for evaluating evidence of school attendance and vocational training for young adults.

Medical Equivalence

SSA should clarify the Introduction to ensure that people who have a medically determinable impairment (even if the condition is not listed as a specific listing) and also meet either the "B" or "C" functional criteria qualify as disabled.

"A" Criteria Issues Regarding Specific Listings

"Marked" as a Factor

SSA should clarify the "A" criteria so that functional aspects of a particular diagnosis do not create an additional requirement above the "B" or "C" functional requirements.

Traumatic Brain Injury

1. SSA should extend the deferral timeframe for adjudication from the current 6 months to 12 months, where a finding of disability in 3 or 6 months is not possible. SSA must also avoid unnecessarily delaying claims that can be favorably decided within the earlier timeframe.

2. To fully address adjudication of traumatic brain injury under 12.02, SSA should include additional signs and symptoms under the "A" criteria.

"B" Criteria Issues

1. SSA should create a separate section in the Introduction to address several issues regarding the "B" criteria.

2. SSA should expand the descriptions of "activities of daily living", "social functioning," "concentration, persistence, or pace", and "episodes of decompensation" to reflect more recent material currently included in the mental residual functional assessment form and the SSI childhood disability regulations.

3. SSA should clarify the severity level required by replacing "decompensation" with "decompensation or deterioration."

Communication

SSA should include a fifth "B" criteria which addresses the ability to communicate.

"C" Criteria Issues

1. SSA should create a separate section in the Introduction to address several issues regarding the "C" criteria.

2. Particularly in evaluating "C" criteria relating to decompensation, SSA should provide guidance on the need to properly recognize and weigh evidence from non-physician professional sources.

3. Remove "medically" from "medically documented history" to ensure that critical non-physician evidence is not ignored.

Factors Relevant to Disability Determinations

SSA should create a new section in the Introduction to address concepts found elsewhere in SSA policy which are relevant in determining disability, including effects of structured settings, stress and mental illness, extra help, unusual settings, effects of medication, and effect of treatment.

Mental Retardation

Diagnosis

1. Sections 12.05 A. and B. and Sections 112.05 B. and C. should remain in the listing as criteria for determining disability for people with mental retardation.

2. SSA should give applicants the benefit of the doubt and include as disabled those whose IQ scores place them within the standard error of measurement on standardized tests.

3. SSA should continue to use age 22 as the age prior to which onset for a diagnosis of mental retardation is appropriate.

Severity

SSA should continue use of the current Sections 12.05 C. and D. and Section 112.05 D. and should re-evaluate them for setting excessively high standards.

National Research Council (NRC) Recommendations

1. Contrary to the NRC recommendation, people with mental retardation should have their eligibility fully evaluated for mental retardation along with any other impairment that they may have.

2. SSA should adopt the NRC recommendation to remove work disincentives by "considering individuals with mental retardation to be presumptively re-eligible throughout their lives, if they have previously received benefits, subsequently secured gainful employment, and then lost that employment."

3. SSA should reject the NRC recommendation to use composite IQ scores only and, instead, continue its long-standing policy of using the lowest of the full-scale, performance, or verbal scores.

4. SSA should adopt the NRC recommendation to use 1 standard deviation below the mean in two areas of adaptive functioning or 1.5 standard deviations below the mean in 1 area of adaptive behavior as the measure for ascertaining deficits in adaptive behavior that, along with IQ levels 2 standard deviations below the mean, establish listings-level mental retardation.

5. SSA should support more research and development of standardized measures of adaptive behavior.

6. The impact of any modifications that SSA makes to the mental retardation listing must be applied only to new applicants, not in continuing disability reviews and not to 18-year-olds in SSI.

Testing

1. Where children have Individualized Education Programs in their school files, SSA should routinely request test results that are a part of the applicant's file.

2. SSA should only use consultative examiners who use current test instruments for IQ or adaptive behavior tests.

3. Where out-of-date tests are in the claimant's file, SSA should request a current test from a CE.

4. If the test in a claimant's file was out-of-date at the time of its administration, SSA should request a current test from a CE.

New Listings Needed

1. A new listing is needed for adults and children for post-traumatic stress disorder.

2. A new listing is needed for eating disorders to cover anorexia nervosa, bulimia, and other types.

3. A new listing is needed for attention deficit disorders for adults.

4. A new listing is needed for Alzheimer's disease.

5. Improvements are needed for the autism criteria for children and adults.

Recommendations of the General Accounting Office

SSA should not adopt the recommendations of the GAO regarding evaluation of claims under corrected conditions and regarding incorporation of potential scientific advances or interventions into the listing.

Other Listing Issues

1. SSA should build upon the work in the SSI children's program to create an effective process for evaluating adults who do not meet specific listings; this could be done by creating a functional equivalence process or to improve the residual functional capacity process for effective assessments, especially for young adults who have no substantial work history.

2. SSA should construct the children's mental disorder listing so that people do not have to refer back and forth between different listings to find the functional criteria.

3. SSA should reinforce the Disability Determination Services' (DDSs) responsibility to use consultative exams to acquire additional or "missing" evidence.

4. SSA should emphasize the use of vocational CEs to collect evidence on medical and social history from individuals and families.

5. SSA should treat evidence from appropriately state-certified clinical social workers as "medical evidence".

Issues Outside the Listings